

ECD Global Alliance
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ECD and the Brain

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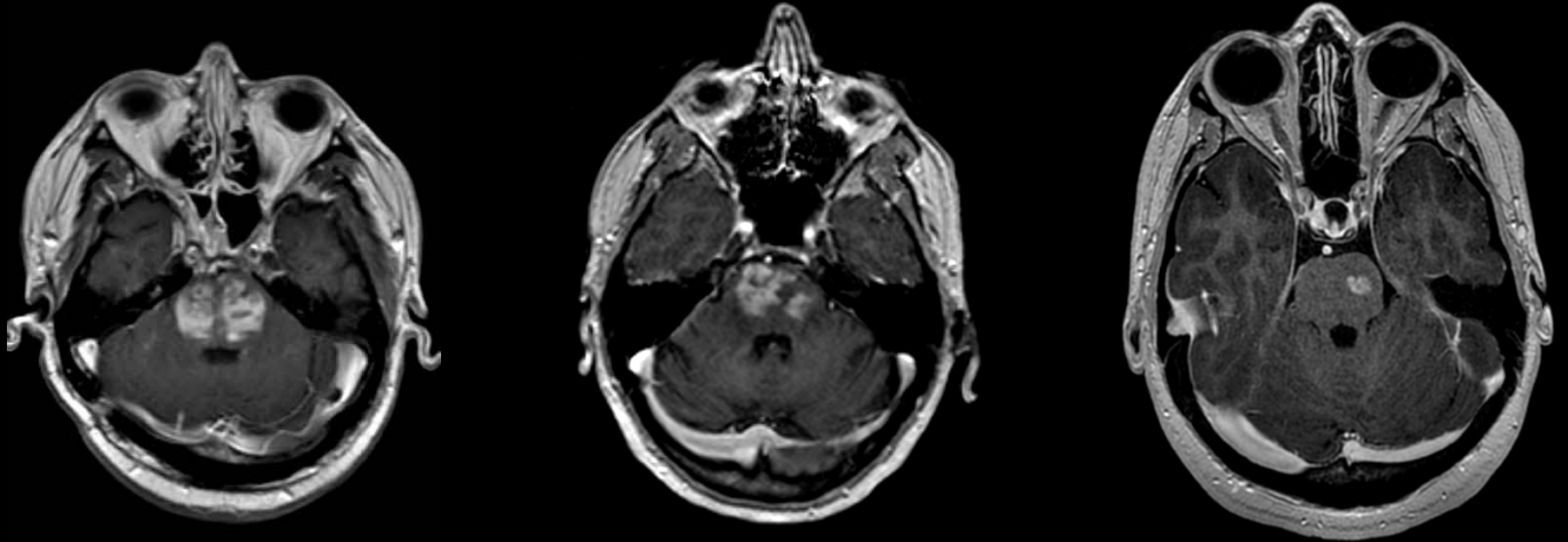
ECD and the Brain: Overview

- **ECD lesions in the brain and spine**
- **Neurologic problems without lesions?**
- **Thinking and memory problems**
- **Other issues and what you can do**

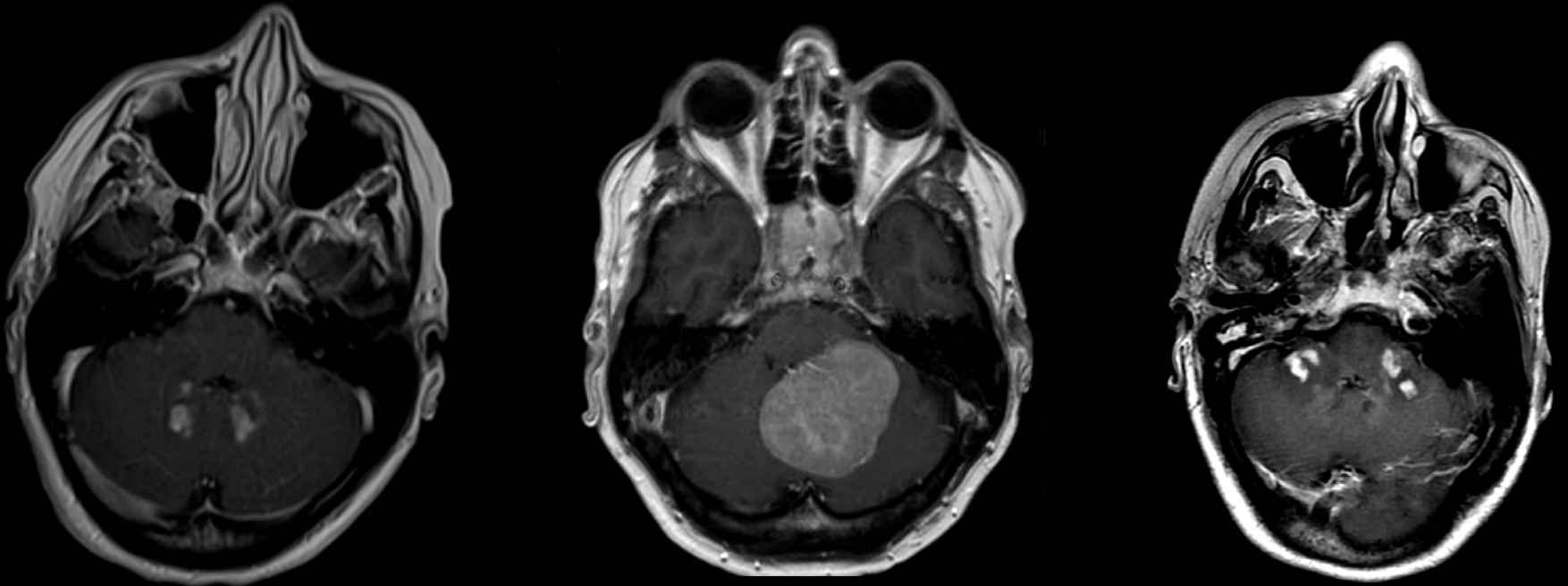
ECD and the Brain

- **~one third of ECD patients have problems in the brain**
- **Most common symptoms are balance problems, speech problems, coordination of arms and legs**
- **More severe symptoms include trouble swallowing**
- **Unusual or inappropriate emotions (laughing/crying)**

ECD in the brain



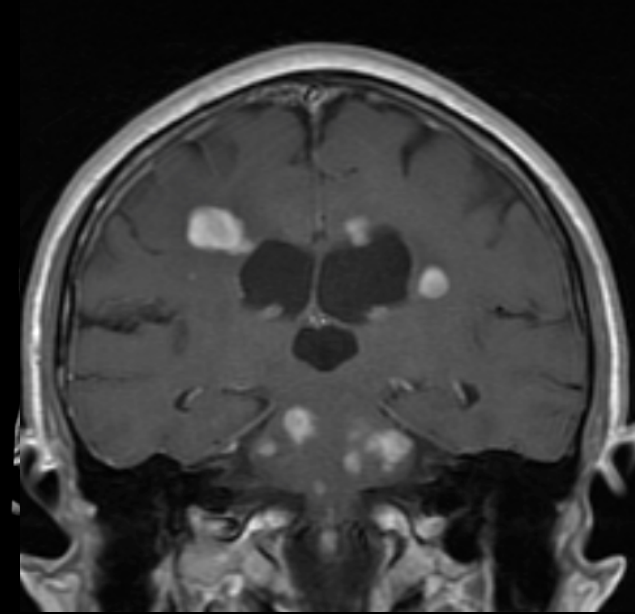
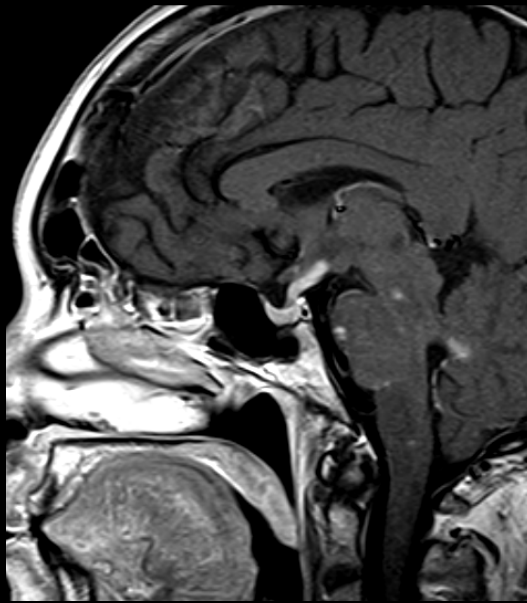
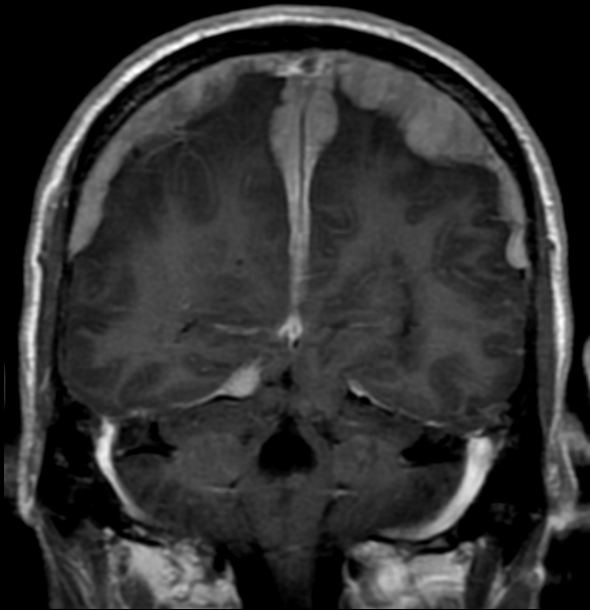
ECD in the brain



Other ECD brain symptoms

- **“dementia”**
- **Incontinence**
- **Hormonal problems including diabetes insipidus**
- **Mood and behavior problems**
- **Depression**
- **Fatigue**

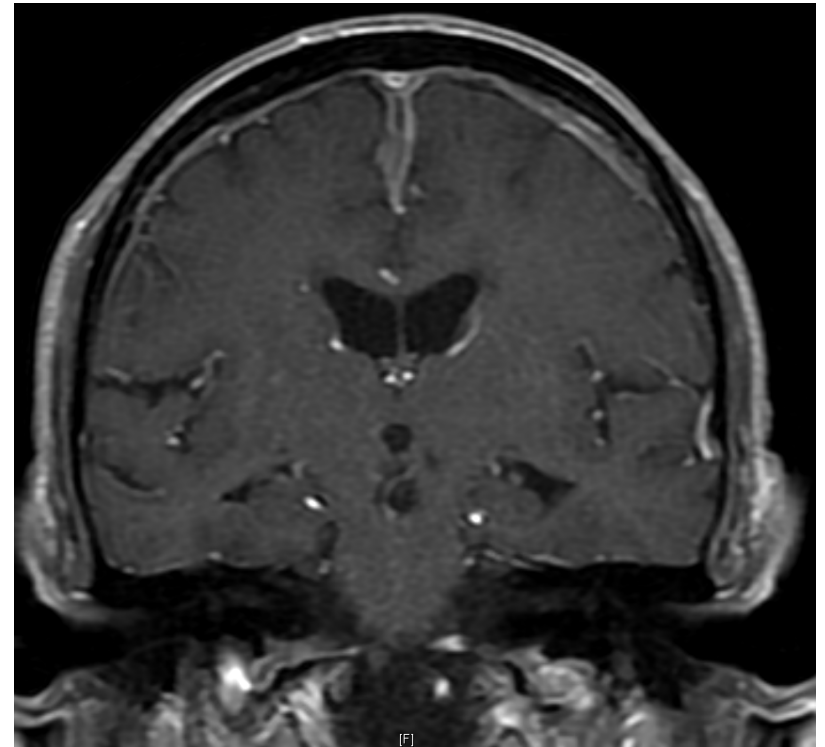
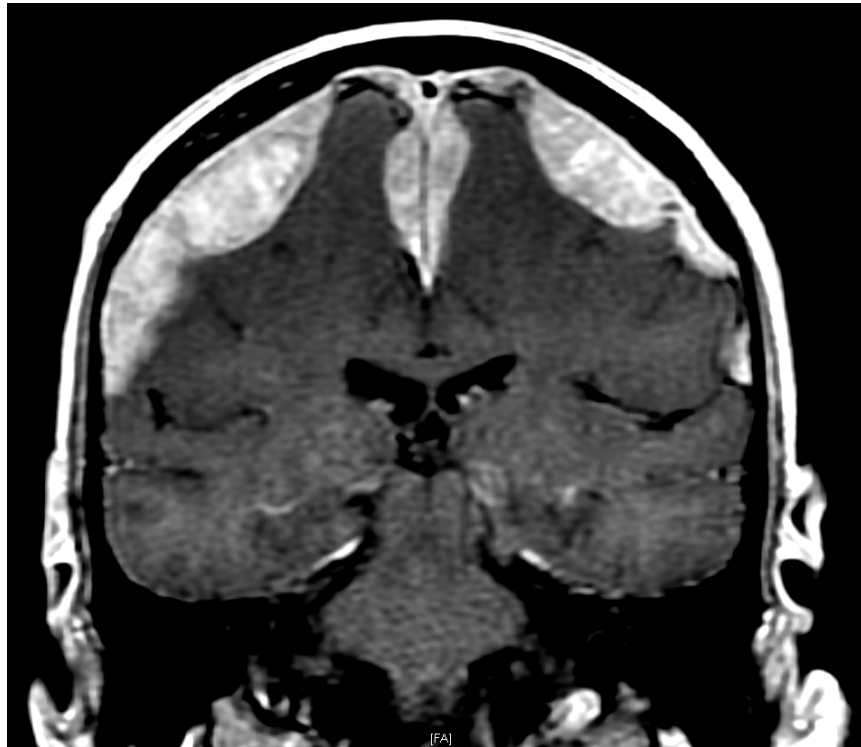
ECD in the brain



ECD in the brain: treatment

- **Probably most difficult form of ECD to treat**
- **Especially if BRAF “negative”**
- **But there are options**
 - **Interferon**
 - **Chemotherapies**
 - **Immune system drugs**
 - **New BRAF-like drugs in trials**

Successful Treatment of BRAF-negative brain ECD

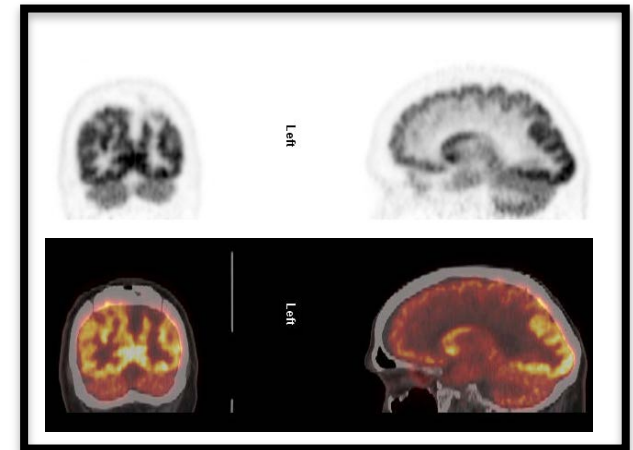
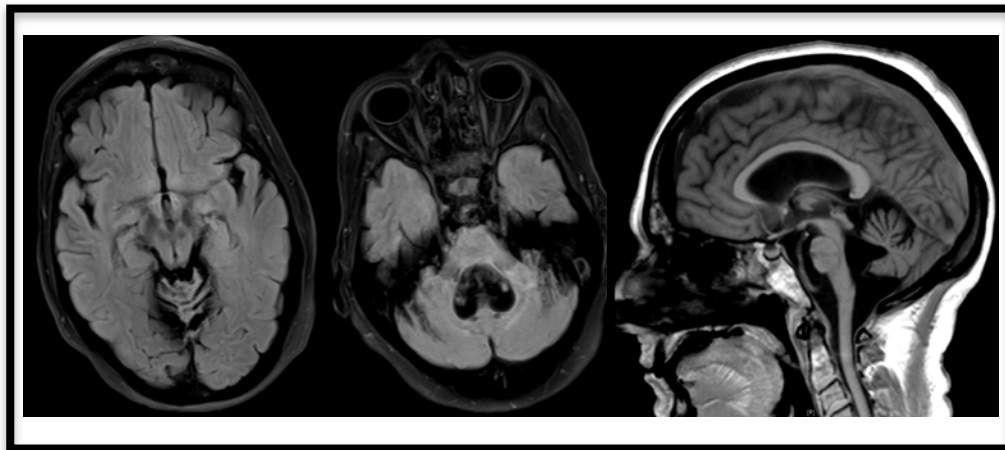
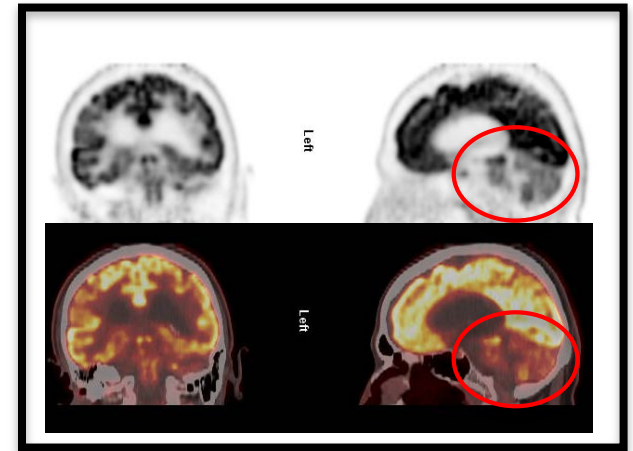


ECD and the spine

- **Not very common, rare in the spinal cord itself**
- **But can affect bones of the spine, nerves in front of the spine**
- **Back pain**
- **Rarely, spinal cord problems if tumors grow and press on spinal cord**

Balance problems without tumors?

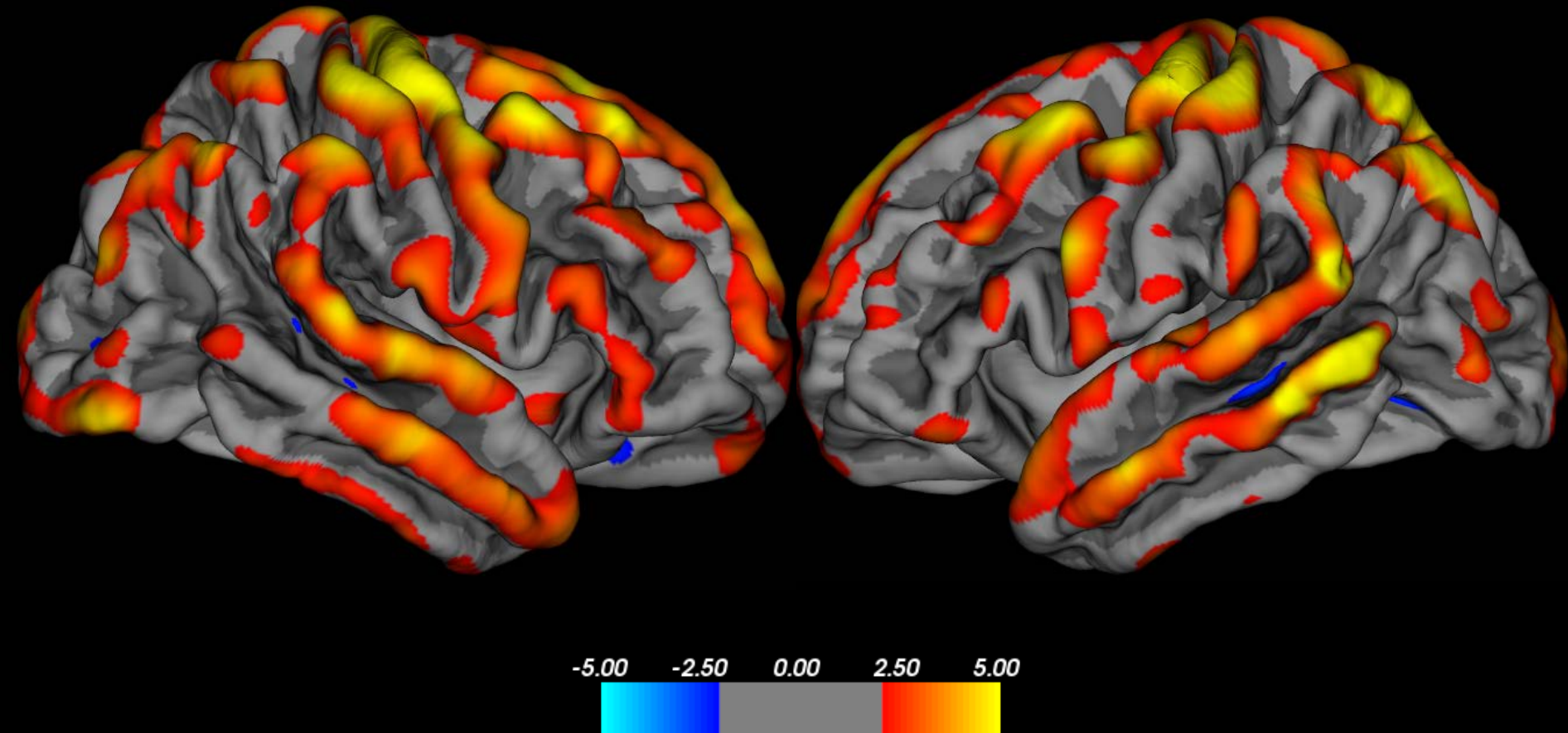
- Many ECD patients have balance problems without a good explanation
- Unsteadiness, falls
- We don't really understand this



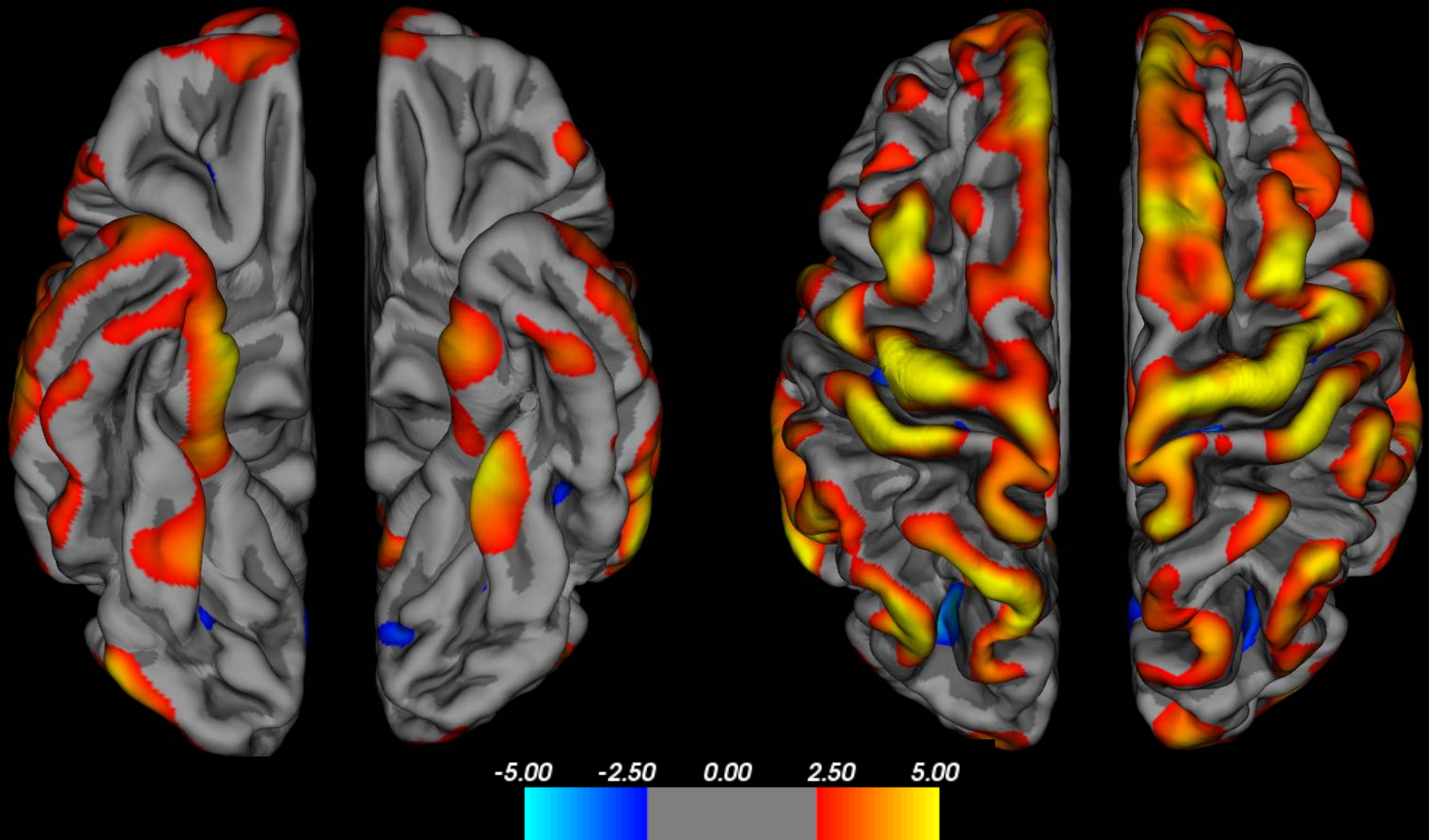
Cognitive Problems in ECD

- **Very common and unrecognized problem**
- **Trouble paying attention, trouble remembering things, multi-tasking**
- **Ability to work normally can be affected**
- **Even patients “without ECD in the brain”**
- **We don’t really know why but we have ideas**

Brain changes in ECD without tumors



Cortical thickness: ECD versus normal



Other neurologic problems

- **Neuropathy (numbness, burning, tingling in the feet) is VERY common**
- **Can also affect balance**
- **Pain can affect quality of life severely**
- **May be related to vitamin or nutritional problems**
- **Pain CAN be treated**

What can you do

- **BE GREEDY with your quality of life!**
- **All ECD patients should have a brain MRI**
- **Be evaluated for neuropathy**
- **Treat fatigue! There are many good medications. And exercise helps.**
- **Treat depression**
- **Get your vitamins and hormones checked**
- **See an ECD specialist if you have unexplained symptoms**

Thanks